

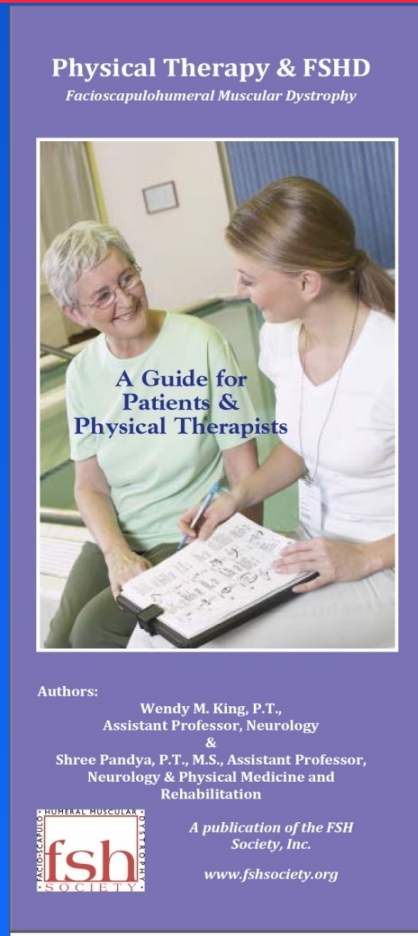
**FSHD CONNECT**  
**Sunday, August 17th, 2014**  
**Boston, MA, USA**

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**UPDATE ON PHYSICAL THERAPY AND  
EXERCISE RECOMMENDATIONS**

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# Physical Therapy In FSHD



Guide developed in 2007

To assist physical therapists and patients develop an individualized plan of care based on the best research evidence, clinician expertise and patient preferences

Much of the information still pertinent

# Physical Therapy In FSHD

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Decision to update Guide to include:

- Current knowledge of genetics
- Molecular pathomechanisms
- Updated exercise recommendations
- Other physical therapy updates
- Accompanying video clips

# Physical Therapy In FSHD

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Goals of the presentation:

- Discuss pertinent information from the guide
- Provide additional updated information based on current literature and consensus recommendations

# Physical Therapy In FSHD

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Goals of physical therapy:

- Maintain optimum health and wellness
- Prevent/delay secondary complications
- Maximize functional abilities
- Improve/maintain quality of life

# Physical Therapy In FSHD

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Requires individualized plans based on individual needs

Plan may include recommendations regarding:

- Appropriate activities and exercises
- Management of pain and/or fatigue
- Orthotics, mobility and assistive devices

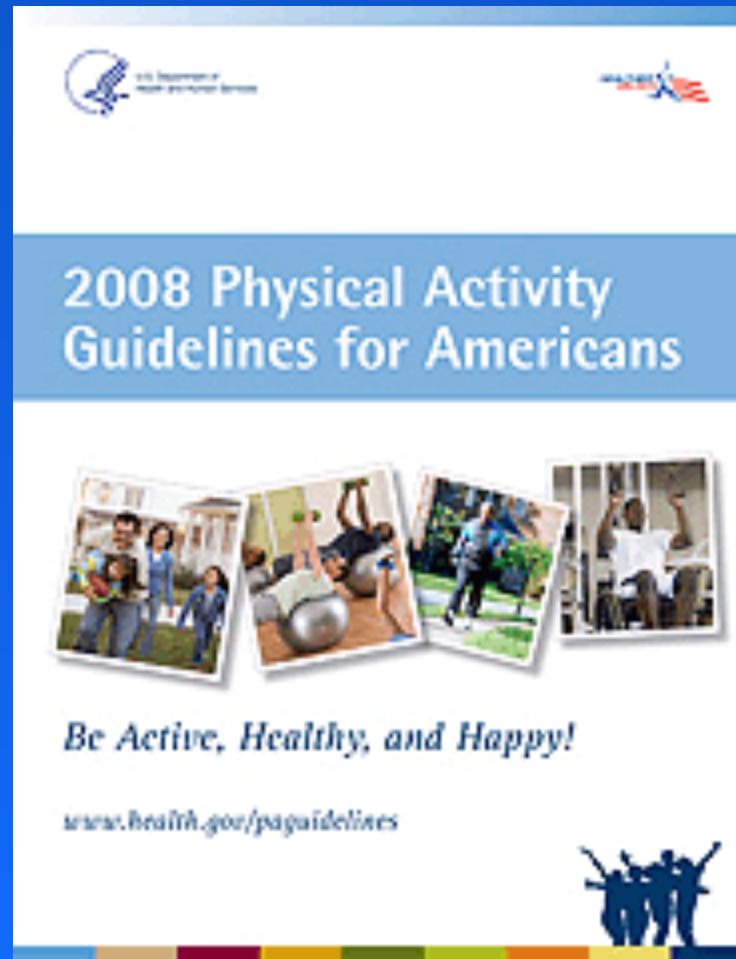
# Physical Therapy In FSHD

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## Documented Benefits of Physical Activity

- Helps control/lose weight
- Reduces risk of cardiovascular disease
- Reduces risk for type 2 diabetes
- Reduces risk of some cancers
- Helps strengthen bones and muscles
- Improves mental health and mood
- Improves ability to do daily activities
- Increases chance of living longer

# 2008 Physical Activity Guidelines for Americans



<http://www.health.gov/paguidelines/guidelines/default.aspx>



# Recommendations from 2008 Guidelines

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## Aerobic activity

- 2 hrs and 30 minutes (150 minutes) of moderate intensity aerobic activity every week
- Spread your activity out during the week  
30 minutes x 5 days = 150 minutes
- Break it up into smaller chunks of time during the day. 10 minutes at a time is fine
- Moderate intensity activities are activities where you can still carry on a conversation such as brisk walking, raking, mowing, cycling, line dancing

# Recommendations from 2008 Guidelines

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## Strengthening activities

- 2 or more days a week of muscle strengthening activities that work all major muscle groups (legs, hips, abdomen, back, shoulders and arms).
- Using body weight, free weights, elastic bands, hydrotherapy or equipment for resistance.

# Recommendations from ACSM

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## American College of Sports Medicine

- Position Stand: Garber et al 2011. Med Sci Sports and Exes 2011 July; 43(7):1334-59.
- Quantity and quality of exercise for developing and maintaining cardiorespiratory, musculoskeletal and neuromotor fitness in apparently healthy adults: guidelines for prescribing exercise.

# Recommendations from ACSM

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- Recommendations can also be used to develop individualized plans for adults with chronic diseases and disabilities.
- In addition to aerobic, strengthening and flexibility exercises also recommend neuromotor exercises for balance, agility and coordination.

# Current Recommendations for Individuals with FSHD

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## Exercise/Activities

- Aerobic/cardiovascular
- Strengthening
- Flexibility/range of motion
- Hydrotherapy/pool
- Recreational activities

*(Based on ENMC International Workshop 2010)*

# Evidence for Current Recommendations in FSHD

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- “Aerobic training is safe and can improve fitness effectively in patients with FSH dystrophy” *Orngreen, 2005*
- “There is level II evidence (likely to be effective) for strengthening exercises in combination with aerobic exercises for patients with muscle disorders” *Cup, 2007*
- “Moderate intensity strength training appears not to do harm but there is insufficient evidence to conclude it offers benefit” *Cochrane Review, 2010*

# Current Recommendations For Individuals With FSHD

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- Range of motion (ROM) or stretching exercises
- Active, Active/Assisted, Passive
- Preferably performed daily
- May help decrease pain

# Current Recommendations for Individuals with FSHD

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## Hydrotherapy/Pool Exercises

### Advantages

- Buoyancy
- Provides Assistance/Resistance
- Temperature

### Disadvantages

- Dressing/undressing
- Accessibility



# Current Recommendations for Individuals with FSHD

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## Recreational Activities

- Walking
- Cycling
- Swimming
- Dancing
- Gardening

# Physical Therapy In FSHD

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## Neuromuscular Electrical Stimulation (NMES)

- Has been studied for decades in individuals with muscular dystrophies and other chronic conditions causing atrophy and weakness
- Prevent disuse atrophy
- Provide passive strengthening

# Physical Therapy In FSHD

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Colson S et al. NMES training: a safe and effective treatment in FSHD patients. Arch Phy Med Rehabil 2010; 91:697-702.

- Open pilot trial
- Included 9 individuals with FSHD
- Stimulation of deltoids, trapezius and quadriceps
- 5 days/week for 5 months

# Physical Therapy In FSHD

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Authors concluded

- NMES appears to be safe, feasible, and well tolerated
- Requires further study
- Longer term effects (>6 months)
- Multisite studies with more participants

# Physical Therapy In FSHD

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## Pain in FSHD

- 50-85% of patients report pain
- Most common sites include shoulder girdle, low back, and legs
- Pain affects quality of life
- Medications, heat, massage, etc. have all been used
- No controlled trials reported

# Physical Therapy In FSHD

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Abdominal support  
may help relieve  
low back pain



# Physical Therapy In FSHD

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## Fatigue in FSHD

- 60% of patients report severe fatigue.
- Fatigue related to age and level of impairment
- Energy conservation strategies as well as aerobic exercises have been found to be helpful

# Physical Therapy In FSHD

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## Falls in FSHD

Horlings CG et al. Epidemiology and pathophysiology of falls in FSHD. J Neurol Neurosurg Psychiatry 2009 Dec; 80(12):1357-63.

- Weakness is an important risk factor.  
Relationship between weakness and falls has not been documented in FSHD



# Physical Therapy In FSHD

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## Falls in FSHD

- Studied prevalence, circumstance and consequence of falls
- Used a Questionnaire and Prospective 3 month follow up
- Included 73 patients with FSHD, 49 matched healthily controls, assessed strength and balance in a subgroup of 28 patients

# Physical Therapy In FSHD

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## Falls in FSHD

- 30% of patients reported falling at least 1/month
- 70% of these reported injuries
- Falls occurred at home
- Fell usually in a forward direction
- Fallers were unstable on stairs, on rising from a chair, and while standing with eyes closed
- Frequent fallers had greater weakness

# Physical Therapy In FSHD

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Factors affecting individual recommendations:

- Age (pediatric/adult)
- Clinical profile (current status)
- Personal profile (work, family role, interests, financial/environmental/social barriers & facilitators)

# Implementation

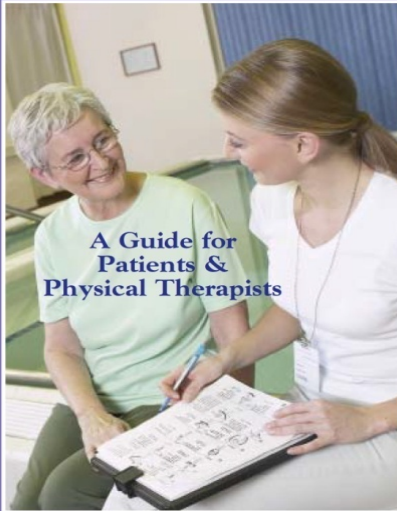
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- Evaluation by healthcare provider(s)
  - Recommendations from health care provider(s)
  - Regular monitoring and adjustments as necessary by provider(s)
  - Self monitoring
  - Trial of at least 3 months before evaluating benefits
- (Providers may include primary care provider, neuromuscular specialist or rehabilitation specialist)

# Physical Therapy In FSHD

## Physical Therapy & FSHD

*Facioscapulohumeral Muscular Dystrophy*



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- Teamwork/Partnership essential for success

# Physical Therapy In FSHD

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## AFO's



# Physical Therapy In FSHD

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## Assistive Devices



# Physical Therapy In FSHD



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# Physical Therapy In FSHD

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Factors to consider when recommending orthotic and assistive devices:

- Strength and functional abilities
- Caregiver assistance
- Environment
- Cost (home modification, transportation)

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